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Nacionalni kontekst misije rak in vmesna evalvacija

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Zakaj misija rak, zakaj integrirati R&I in politike ukrepanja na nacionalni in lokalni nivo?

- Horizon Europe Framework Programme for Research and Innovation (2021-2027) 5 misij za največje izzive.
- Staranje, nezdrav življenjski slog, neugodne družbeni, socialni, okoljski, delovni in življenjski pogoji snujejo veliko breme: državljanom, bolnikom z rakom, preživelim in njih družinam, zdravstvenemu sistemu in družbi sploh.
- Potrebne so konkretne rešitve. Cilj je : “Do 2030, rešiti vsaj 3 milijone življenj, da bodo ljudje živel dlje in bolje”.
- Odbor Misije Rak predstavil 13 priporočil, da bi razumeli raka, z njim povezane dejavnike tveganja, da bi zadržali kar je možno, da bi optimizirali diagnostiko in zdravljenje, da bi podprli kakovost življenja z rakom in po njem, hkrati pa poskrbeli za enako dostopnost.

European Missions-Cancer Implementation plan, 2021

Missions, or “moon shots”, should have a break-through or transformative potential for science, technology, industry or society.

13 priporočil Misije Rak

1. Lansirati UN_CAN - evropsko pobudo razumeti raka.
2. Razviti EU program za odkrivanje (več) genetskih tveganj raka.
3. Podpreti razvoj in izpeljavo uspešnih strategij preventive pred rakom in politik ukrepanja držav članic in EU.
4. Optimirati obstoječe presejalne programe in razviti nove pristope screeninga in zgodnjega odkrivanja.
5. Pospeševati in izpeljevati pristope personalizirane medicine za vse bolnike z rakom v Evropi.
6. Razvijati EU raziskovalni program zgodnje diagnostike in minimalne invazivnosti zdravljenja/tehnologije.
7. Razvijati EU raziskovalni program in podporo politik, da se izboljša kakovost življenja bolnikov z rakom, družinskih članov in negovalcev ter oseb s tveganjem raka.
8. Zasnovati Evropski digitalni center za bolnike z rakom in preživele zaradi hrambe podatkov njihovo delitev v personaliziranem pristopu.
9. Doseči enakost zdravja raka skozi celoten potek bolezni.
10. Vzpostaviti mrežo celostne infrastrukture za celotno obravnavo raka, znotraj in med državami članicami EU z namenom, da se poveča kakovost raziskovanja in nege.
11. Otroški rak, rak pri mladostnikih in mladih odraslih: več in boljše zdravljenje/nega.
12. Spodbuditi inovacije in izpeljavo novih tehnologij, za spopad z rakom snovati žive laboratorije.
13. Transformirati kulturo raka, komunikacijo in krepiti kapacitete.

Nacionalni kontekst misije rak

Namen misije

- Nov instrument 2021-2027, znanje+znanost+R&I+ skupaj vsi akterji+aktivacija državljanov za trajnost
- Socialna inovacija – splet prebojnih aktivnosti, nujen za družbeno-ekonomsko odpornost in razvoj (vse v kontekstu European Green Deal, Digital Strategy - Digital Agenda for Europe, UN Agenda 2030 za razvoj, ki vzdrži, SDG 3 je zdravje).
- Zdravje vrednota, pravica + EU koncept zdravja + dejavnik produktivnosti posameznika in družbe → dodana vrednost

EU dodana vrednost Misije Rak

- dopolnjuje EU plan obvladovanja raka, EBCP.
- povezuje ministrstva zdravstva z ministrstvi R&I→snovanje politik na dokazih/podatkih:
 - nova Priporočila sveta za screening,
 - Uredba o evropskem prostoru podatkov zdravja,
 - UNCAN.eu+cancer research data hub,
 - Medicinski Forum raka/EMA, ki spodbuja akademske klinične raziskave,
- integrirano snovanje politik in prelivanje učinkov med državami+ kreacija Cancer Mission Hubs.

EU Missions two years on: An assessment of progress in shaping the future we want and reporting on the review of Mission Areas and areas for institutionalised partnerships (komunike EU Parlamentu+Svetu in Commission Staff Working Document)

[https://ec.europa.eu/transparency/documentsregister/detail?ref=SWD\(2023\)260&lang=en](https://ec.europa.eu/transparency/documentsregister/detail?ref=SWD(2023)260&lang=en)

4 specifični cilji Misije Rak

- Izboljšati razumevanje raka
- Preventiva
- Optimirati diagnostiko in zdravljenje
- Podpora kakovosti življenja.

In 4 operativni cilji (horizontalni, v vseh ukrepih):

- Spodbujati R&I skozi snovanje znanja in podatke
- Spodbujati inovacije, testirati, vrednotiti, demonstrirati in nadgrajevati rešitve (Living labs)
- Slediti napredek in neenakosti glede pristopa do znanja, raziskovanja in nege (care) /monitoring, podpora in indikatorji)
- Angažiranje skupnosti, državljanov, pacientov in širše družbe (zdravstvena pismenost, komuniciranje).

Razumeti

1. Vzpostavitev platforme UNCAN.eu (2021-2023)
2. Bolje razumeti zdrave in rakaste celice ter vplivi tveganj (življenjski stil, fizična aktivnost,...) (2021-2028)
3. Bolje razumeti bolnika z rakom: molekularne, celične, organske in interakcije organizma, novi modeli, biomarkerji (2023-2029)
4. Opredeliti vlogo genetike pri raku: od razumevanja, novih modelov, organiziranja in sinergij znanj (2024-2030).

Preventiva +screening in zgodnje odkrivanje

Preventiva:

1. One-stop info center za preventivo raka (2022-2025)
2. Spodbujati R&I zaradi ocene tveganj: kemikalije, kancerogenost okolij) (2024-2027)
3. Izpeljava raziskav za rešitve preventive na nivoju lokalnih skupnosti: tobak, alkohol, radon, onesnaženost vode, zemlje, zraka, hrane, tudi pismenost glede zdravja...(2022-2030)
4. Sinergija Misije Rak z misijami: Adaptation to climate change including societal transformation; Healthy oceans, seas, coastal and inland waters; Climate-neutral and smart cities; Soil health and food.

Screening in zgodnje odkrivanje:

1. Optimirati in izboljšati dostop do obstoječih presejalnih programov (2024-2029)
2. Razvoj novih metod in tehnologij screeninga in zgodnjega odkrivanja (2021-2026)
3. Razviti zgodnje napovedi (2025-2030).

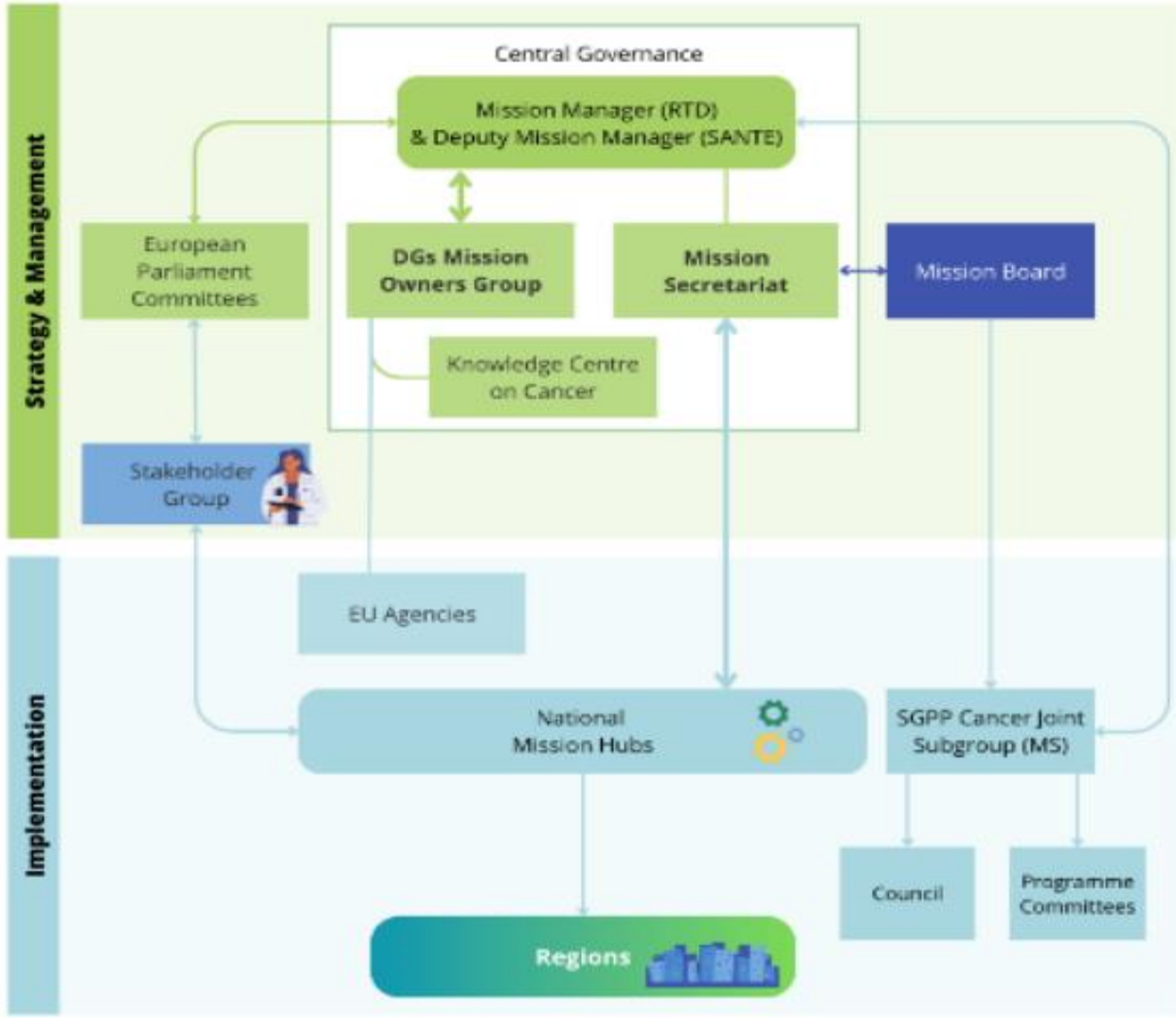
Optimirati diagnostiko in zdravljenje

1. Mreža celovite infrastrukture Network of Comprehensive Cancer Infrastructure (2021-2025), do leta 2030 90% dostop
2. Twinning programi (2024-2028)
3. Razvoj programov klinične obravnave diagnostike (2023-2027)
4. Razvoj programov kliničnega zdravljenja (2022-2023).

Podpora kakovosti življenja

1. Zbirati in analizirati podatke o neuresničenih potrebah bolnikov raka in preživelih (2021-2025)
2. EU digitalni center pacientov z rakom (2021-2023) za personaliziran pristop
3. Razviti zgodnje napovedovalce kakovosti življenja (2024-2030)
4. Načrti programov monitoringa za preživele z rakom v otroštvu (2021-2027)

Figure 5: Governance structure for the Cancer Mission



Source: EFIS study based on Mission Implementation Plan (EC, DG RTD 2021c, p.35)

Note: SGPP Cancer Joint Subgroup is now called a joint sub-group on cancer under the Public Health Expert Group

VMESNA EVALVACIJA

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Na nivoju EU:

- Izziv povezava med Misijo in ECBC (str. 34: Misija je v hierarhiji ukrepov politik više – kar pomeni, da je Evropski program obvladovanja raka, EBCP del misije)
- Management arrangements and governance structure (EC DG Sante+DG RTD)
- Od sept. 2022 2. mission board (koalicije, ambasadorji, nac.in lokalno)
- +EU Parlament, +Svet

Za kontekst države – po vmesni evalvaciji dejavniki, ki omogočajo rezultate misije (str. 40)

1. Učinkovita koordinacija med EK, nacionalnimi, regionalnimi in lokalnimi nivoji.
2. Pristop misije = multi governance model (→ njegova kompleksnost je lahko vzrok, da v državi še ni vzpostavljena struktura v podporo Misiji).
3. ↑Mission Hubs, Zrcalne skupine/Mirror groups - pripomorejo k integraciji aktivnosti Misije, podpirajo dialog politik glede preventive in obvladovanja raka.
4. Resna zaveza in vpletenost deležnikov (+↑bottom up).
5. Koherentnost med razpoložljivim financiranjem in cilji misije.
6. Vključenost državljanov.

Vrsta dejavnika in pričakovan vpliv na misijo (Vmesna evalvacija, Tabela 15).

Table 15: Identified factors or possible trends influencing the Mission Area

Type of factor/trend	Short summary of the expected impact of the factor/trend
Economic: workforce crises, need for competence development	If insufficient workforce available in prevention, health care, and nursing, this will create bottlenecks in cancer treatment and care and could potentially increase cancer cases
Geopolitical: refugees crises due to wars and climate change	Increasing pressure on the healthcare systems of the countries accepting refugees. Equality of access to care and treatment will become higher on the health agenda.
Policy: the need to share data and opportunities offered by the European Health Data Space (EHDS)	Potential positive effect on cancer research and treatment. Individual having control over their health data could support them in seeking faster cancer treatment across the border.
Policy: the possibility to share data for altruistic purposes in the Data Governance Act	Positive effect on cancer research and treatments thank to altruistic data sharing for purposes of general interest
Policy: new directive from EMA regulating clinical trials, new directive on medical devices	Potential to influence the speed of introduction of medical innovation to market / healthcare system. This in its turn will improve cancer diagnostics and treatment
Scientific: cancer becoming more and more a chronic disease	Reforms in the health and care system might be needed to cope with the long-term nature of the disease. Quality of Life will become higher on the agenda.
Social: major needs for quality of life and survivorship (e.g. tertiary prevention)	Reforms in the care system might be needed.
Technological: use of AI/machine learning cancer diagnostics, radiology, new technologies for screening	Cancer cases identified faster, thus increasing the likelihood of survivorship. AI-driven imaging help improve consistency and reduce workload. Screening in itself could contribute to changing people's attitudes towards cancer and becoming more active in prevention.

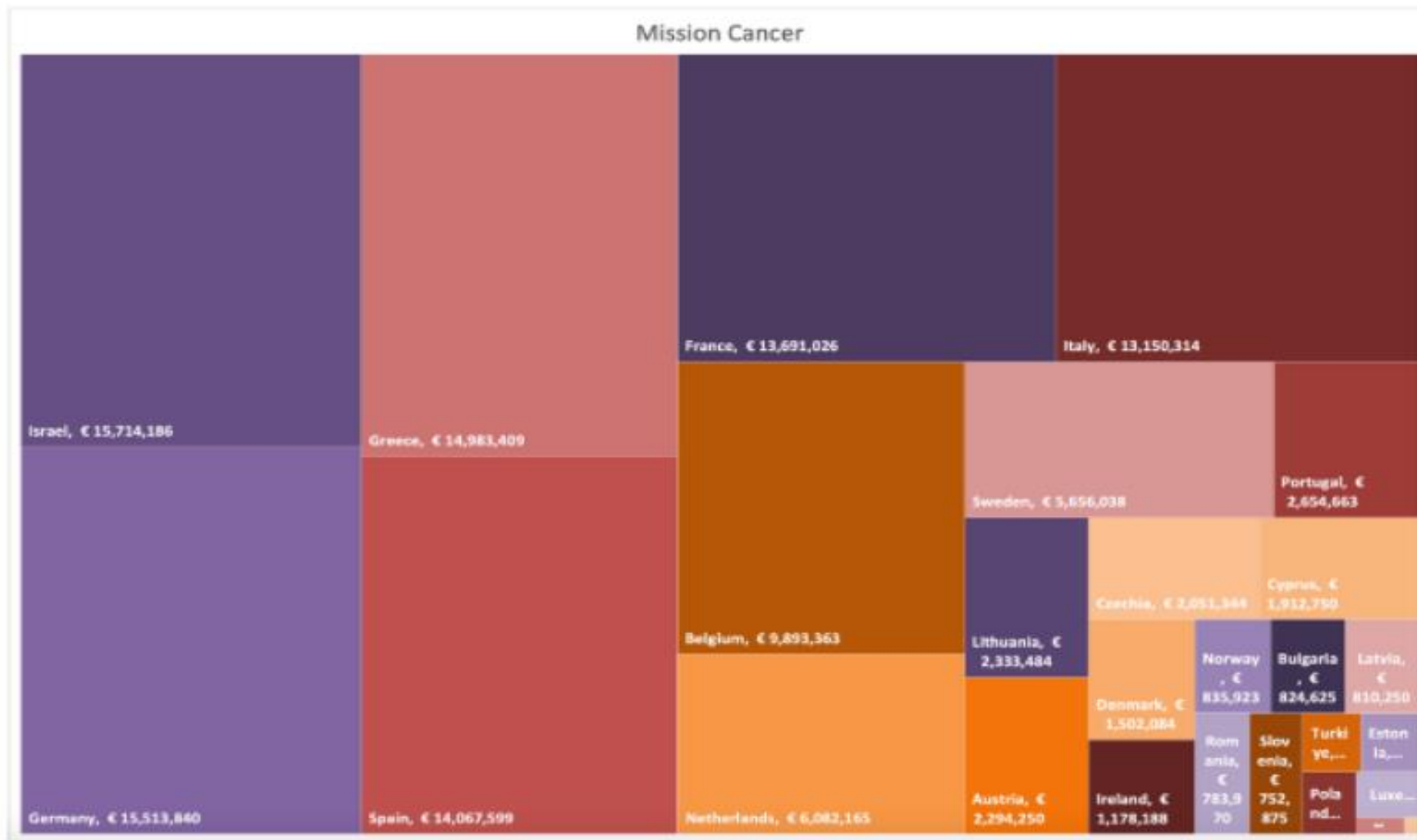
Source: external study team

Fokus misije = strategija (R&I) in odpornost sistemov (resilience+recovery)

Forward-looking Issues

FLI 1: Digitalisation and security and privacy issues	FLI 4: Resource scarcity issues	FLI 7: AI and Robotics in health services	FLI 10: Bioeconomy issues	FLI 11: Sustainable mobility for climate
FLI 2: Digitalisation, AI and automation in the economy	FLI 5: Food and food system transformation for climate	FLI 8: (Hyper)connectivity in life and the economy	FLI 12: Recyclability, sustainability and the circular economy	FLI 14: Changing life and consumption patterns
FLI 3: Decarbonisation of the economy	FLI 6: Alternative energy sources and systems transformation	FLI 9: Space and military technologies and defence issues	FLI 13: Shifts in health research and healthcare approaches and systems	FLI 15: Increased importance of advanced manufacturing

Figure 6: Horizon Europe Mission Cancer project funding per country



Source: Horizon Europe Dashboard. Data extracted 21 March 2023. Analysis and visualisation: authors

Ključne ugotovitve

- Misija EU je ambiciozna, navdihuje, a ostaja realna.
- Naslavlja kritične spremembe v družbi.
- Zajame predpogoje in bo prišlo do sprememb za paciente, njihove negovalce, družine in državljane.
- Ker so iste ključne aktivnosti Misije in ECBC so potrebne močne povezave, model združenega managementa (joint management model)→sinergija in koherentnost.
- Misija je več kot R&I (izobraževanje, lokalna skupnost, preventiva, šport...)

Priporočila za Države članice EU – ključne aktivnosti Misije (str.37)

- Poravnava politike ukrepanja EU in države, misija, strategija, sinergije, trans sektorska mobilizacija eur, sodelovanja (→kapaciteta, mirror groups (zaenkrat v A,B,P,E)).
- Sinergija DPOR (programa obvladovanja raka) z misijo.
- Organiziranost (governance, management): ne le za misije -tudi raziskovalni programi, sistemi (javno zdravstvo,...), prioritete in razpoložljivost resursov.
- Obvladovanje Misije (Mission governance): poravnava med EU, državo in lokalno; vsi sektorji, javno, zasebno, civilna družba, jasno določene strukture misije in odgovornost.

2021-2023 najmanj še 400 mio investirano za spec. cilje Misije Rak:

Poleg Obzorja (MISS) 365mio

Program Digitalna Evropa za cancer images data (pobuda Cancer imaging initiative 18 mio

EU4Health programme 2021-2022 226,9 mio EUR grants+3 javna n.za misijo

EU4Health programme 2023 še 187,3 mio EUR

Recovery and resilience facility n.pr. Češka, Hrvaška, Grčija

Misije so pobude, ki dajejo v pravem trenutku nov zagon pomembnim prioritetam EU.

Misije usklajujejo napore politik EU, države, regij in lokalnih oblasti do ciljev, ki so skupni.

Misije dajejo navdih skupnim angažmajem in aktivni participaciji vseh deležnikov.

So tudi aktivacija državljanov in lokalnih skupnosti.

Table 4: Summary of progress towards Mission objectives

Specific objectives / Operational objectives / Cross-cutting	Implementation steps taken	Challenges ahead (identified in interviews, survey and desk research)
<p>SO1. Improve the understanding of cancer</p>	<ul style="list-style-type: none"> • Ongoing work to build project portfolio • Started project to establish the ‘UNCAN.eu’ platform with a blueprint being currently developed 	<ul style="list-style-type: none"> • Make the blueprint from UNCAN.eu into a full-fledged and functioning platform managed by MS, AC and stakeholders • Further budget needed to build on future actions
<p>SO2. Prevent what is preventable through screening and early detection</p>	<ul style="list-style-type: none"> • Acquired guided terms of reference for consultation of EC proposal for update of Council recommendations on cancer screening 	<ul style="list-style-type: none"> • Understanding and eliminating barriers for previous prevention steps (e.g. why screening programmes did not happen in all countries) • Bringing synergies with other Missions into a reality, e.g. better soil, cleaner cities and better climate can reduce some causes of cancer • Involvement of primary care considered by some interviewees as a potential challenge in some countries
<p>SO3. Optimise diagnostics and treatment</p>	<ul style="list-style-type: none"> • Ongoing projects around the CCI (e.g. CRaNE) • The CCC network to be created by 2025 to integrate care, research, training and awareness • Developed a clinical trials programme on treatment 	<ul style="list-style-type: none"> • Not allow ‘oncopolitics’ to deliver an innovative and comprehensive approach to diagnostics and treatment • Ensure sustainability of CCC by bringing synergies of EU-national funding (i.e. some opinions exist

Specific objectives / Operational objectives / Cross-cutting	Implementation steps taken	Challenges ahead (identified in interviews, survey and desk research)
		that once CCCs are established there will be an ongoing funding stream from the EC).
SO4. Support quality of life	<ul style="list-style-type: none"> Launched development of the blueprint for the European Cancer Patient Digital Centre (ECPDC) 	<ul style="list-style-type: none"> Further budget needed to build on future actions Incorporate the needs of some patients' groups which are currently not visible (i.e. terminally ill patients) ECPDC (was supposed to have been done during 2021-2023) – no proposals submitted – how does it affect the other activities
OO1. Foster Innovation (R&I programme)	<ul style="list-style-type: none"> Ongoing work to build project portfolios 	
OO2. Living labs	<ul style="list-style-type: none"> Current examples are found in Finland ⁽⁴⁰⁾, France ⁽⁴¹⁾, Spain ⁽⁴²⁾ and at a European level ⁽⁴³⁾ 	<ul style="list-style-type: none"> No indication found on the development of additional ones or their funding sources
OO3. Monitoring, support and indicators	<ul style="list-style-type: none"> Initial Mission-specific targets and indicators developed per objective as described in the Mission implementation plan. 	<ul style="list-style-type: none"> Ensuring consistency of Mission-specific monitoring efforts and design with the overall Horizon Europe monitoring system.
OO4. Health literacy, communication, citizen engagement	<ul style="list-style-type: none"> Focus groups Main event and follow-up with young survivors (“Young Cancer Survivors workshops and Conference”, 6-7 February 2023) 	<ul style="list-style-type: none"> Ensuring systematic data collection & feedback from citizen engagement campaigns

